Department of Mental Health

Independent Evaluation of the Traumatic Brain Injury Services of California

Legislative Report

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Background

Over 100,000 Californians visit emergency rooms each year due to head injuries, and an estimated 25% of these individuals never return to work. To address the needs of this population, the Traumatic Brain Injury (TBI) Services of California Project is designed to "demonstrate the effectiveness of a coordinated service approach which furthers the goal of assisting individuals with TBI to attain productive, independent lives, which may include paid employment." Four of the seven sites listed in Figure A, below, have been part of the TBI Project since its inception in 1990. The Janet Pomeroy Center in San Francisco was funded in 2001, while Central Coast Neurobehavior Center in Morro Bay and Making Headway in Eureka were funded in 2003. Project sites provide four core services—community reintegration, supported living, vocational supports, and service coordination.

Figure A TBI Services of California Sites			
Grantee	Location, Service Area	Year of Contract Award	Referred to in this report as:
Betty Clooney Foundation for Persons with Brain Injury	Long Beach, Los Angeles County	1990	Clooney
Central Coast Center for Independent Living	Capitola, Santa Cruz County	1990	CCCIL
Central Coast Neurobehavior Center	Morro Bay, San Luis Obispo & Santa Barbara Counties	2003	CCNBC
Making Headway, Inc.	Eureka, Humboldt, Del Norte, & Mendocino Counties	2003	Headway
Mercy Healthcare, Sacramento	Roseville, Sacramento, Placer, & Yolo Counties	1990	Mercy
St. Jude Medical Center	Fullerton, Orange County	1990	St. Jude
Janet Pomeroy Center (formerly RCH, Inc.)	San Francisco, San Francisco County	2001	Pomeroy

The objectives of the *Independent Evaluation of the Traumatic Brain Injury (TBI) Services of California* were to: 1) assist in establishing a uniform participant data collection system to evaluate the effectiveness of the individual sites and the program as a whole; 2) describe each site's service model, context, and implementation; 3) identify factors associated with program and participant success; and 4) prepare a report to the Legislature that summarizes study findings and provides recommendations for program improvement and future evaluation efforts. To achieve these

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¹ California Welfare and Institutions Code Section 4353-4359: Traumatic Brain Injury Program

objectives, the evaluation team gathered both qualitative site-visit data and quantitative data on participant characteristics, service use, outcomes, and customer satisfaction.

Summary of Key Findings

Participants Served

As a group, the TBI Project sites served a total of 610 participants in Fiscal Year 2003-2004 (FY03-04). The evaluation examined data from a subset of these participants—a sample of 213 individuals who first enrolled in the program between February 1, 2003 and June 30, 2004. The "typical" TBI Project participant included in the evaluation's study sample is a 41-year old single white male who has attended some college, receives SSI or SSDI, and lives either alone or with a family member.

Over half of participants were injured in a motor vehicle accident, and 28% of participants' injuries were related to use of drugs or alcohol, either by the TBI survivor or another individual. One-quarter of participants had experienced their TBI in the year prior to enrolling in the TBI Project. Overall, however, the average length of time between injury and intake was ten years. Three-quarters of all participants were hospitalized as a result of their traumatic brain injuries, and half experienced a coma. Over a third of all participants experienced amnesia after their traumatic brain injuries.

The sites reported that just over one-third of program participants had a history of substance abuse prior to entering the program. Of these, 87% were no longer drinking or using drugs at intake, and on average had been "clean and sober" for five years at enrollment. However, 18% of participants were identified as having a problem—or suspected of having a problem—with drug or alcohol abuse at the time they enrolled in the program.

At intake, TBI Project staff assessed participants' presenting needs using a list of 26 types of services. These assessments determined that participants in the study sample needed an average of 4.5 services. The most frequently needed services were counseling, self-help/support groups, and vocational rehabilitation.

Only 11% of participants were working when they entered the TBI Project, and another 22% were DR clients. Nonetheless, a full two-thirds of participants expressed a desire to work at the time they enrolled in the program.

Services Provided

The evaluation used two sources of information about services provided by the TBI Project sites: 1) aggregate data from the Project's quarterly reporting system on the number of participants served and number of inquiries during FY03-04; and 2) information collected on the Project's six and 12-month assessment forms about the services used by the 129 individuals in our study sample for whom sixmonth follow-up data was available.

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Staff from the seven sites conducted a total of 363 intakes during FY 03-04. Staff at the four original sites (Clooney, CCCIL, Mercy, and St. Jude) were more likely to complete an intake form for anyone with a brain injury who called the site, while staff at the new programs tended to collect intake data only for those individuals most likely to enroll in services.

TBI Project staff conducted 202 initial assessments during the last fiscal year. The sites completed 106 six-month assessments, 90 twelve-month follow-ups, and 71 eighteen-month follow-up assessments during FY03-04. Site staff developed 369 initial individual service plans (ISPs) during the year. Pomeroy used a different approach to service planning than the other sites by writing a new ISP for each new task. Overall, Pomeroy staff wrote an average of seven ISPs per new participant compared to one ISP per new participant at the rest of the sites.

Virtually all of the 129 participants in the follow-up sample received case coordination services during their first six months in the TBI Project. Substantial proportions of participants also used day program and social/recreation services. Participants enrolled in one of the four original sites (Clooney, CCCIL, Mercy, and St. Jude) were more likely to use day program and social/recreation services than they were to use employment services. In contrast, CCNBC and Pomeroy participants were more likely to use employment services than they were to take part in a day program or social/recreation services. While these differences may be related to the services that each site provides directly, enough variation exists in the pattern to suggest that participant choice of services also is an important factor in the mix of services predominantly provided at each site.

Overall, the TBI Project sites appear to be addressing the needs of their participants. The proportion of individuals in the follow-up sample who needed each type of service decreased between intake and their six-month follow-up. Furthermore, the majority of participants who were identified as needing a service at intake had received the corresponding service by the time of their six-month follow-up.

Evaluation Results

Below, the key results of the evaluation are organized according to the four major requirements for the evaluation that are specified in California Welfare and Institutions Code Section 4353-4359.

1. The degree of community reintegration achieved by participants, including their increased ability to independently carry out activities of daily living, increased participation in community life, and improved living arrangements.

The evaluation's primary measure for assessing the degree to which TBI Project services help to improve participants' reintegration into their communities was the Community Integration Questionnaire (CIQ). This instrument was specifically designed to measure community integration among survivors of traumatic brain injury, and includes three different subscales—home integration,

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² The source of this data was participants' six-month assessment. At the time that data was collected for this report, none of Making Headway's participants had been enrolled in the program long enough for staff to complete a six-month assessment.

social integration, and productivity. The CIQ results are reported for the 129 participants for whom data is available at both intake and follow-up.

Across all the sites, two-thirds of participants experienced a change in total CIQ score during their first six months in the program. The average increase among those who experienced any change was about three points, from 11.8 at intake to 14.9 at six months. Because those who experienced a positive change tended to be individuals who had relatively low CIQ scores at intake (and therefore those who could most benefit from Project services), this increase represented an average increase of 64% over their initial total scores.

In addition to the CIQ, we examined various changes in day and vocational program participation, education and employment status, income source, and living situation. We classified changes as being either positive (e.g., entered employment, moved out of a skilled nursing facility, secured more stable source of income) or negative (e.g., moved into a more dependent living situation with family members; decreased participation in, or left a day program without entering employment). Almost three-quarters (72%) of participants for whom data was available at six months had at least one positive outcome, while only 20% experienced any negative outcomes.

2. The improvements in participants' prevocational and vocational abilities, educational attainment, and paid and volunteer job placements.

Vocational improvements were measured using the following indicators: increased educational attainment; entered a vocational program; increased participation in a vocational program; became a DR client; or obtained employment. Across the seven sites:

- 5% of participants increased educational attainment;
- 5% entered a vocational program;
- 8% became a DR client; and
- 6% obtained employment.

Across all of these measures, 22% of participants showed at least one type of vocational improvement. A number of factors may explain these fairly limited vocational outcomes. First, most participants have multiple impairments as a result of their TBI, and some participants experience relatively severe impairments. Second, despite recent changes in Social Security regulations, disincentives for employment still exist in public benefits systems. Third, the TBI Project was not designed as an employment program, and thus getting a job is only one of many outcomes for which the sites provide assistance. In fact, only some of the sites have a strong vocational emphasis. Finally, the observation period for the study was relatively short, and more participants may move toward vocational goals over a longer follow-up period.

3. Participant and family satisfaction with services provided.

Over three-quarters of the 160 participants who completed the evaluation's mail survey of customer satisfaction "agreed" with each positive statement on the questionnaire, and the majority "strongly agreed" with each statement. Only 15 respondents replied negatively to any one of the nine survey questions.



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Compared to participants from the newer sites, participants of the four original sites (Clooney, CCCIL, Mercy, and St. Jude) tended to respond more positively to survey statements about receiving needed information and assistance, receiving information in a way they could understand, dealing more effectively with daily problems as a result of the Project's assistance, being better able to control one's life since participating in the Project, and willingness to use services again. On the other hand, participants served by Headway and Pomeroy tended to be slightly more positive about their site's ability to develop service plans with their individual goals in mind, and CCNBC participants were more likely than those served by other sites to believe that program services improved their ability to deal effectively with daily problems.

Overall, TBI Project participants were extremely positive about the program and appreciated the services they received. As a participant wrote on his survey, "Thank you for having these services. Nobody plans on being a TBI survivor or it happening to them until it happens, and then you need all the help you can get."

Feedback from participants and their families collected during site-visit interviews was similarly glowing. The participants interviewed were extremely pleased with the services they received and appreciated the assistance and care they received from the staff on site. The most frequent compliments revolved around the uniqueness of the services available for TBI survivors. Participants and family members remarked that the individualized services offered by the sites were not readily available to them from any other source.

4. Number of participants, family members, health and social service professionals, law enforcement professionals, and other persons receiving education and training designed to improve their understanding of the nature and consequences of traumatic brain injury, as well as any documented outcomes of that training and education.

The TBI Project sites provide several different types of community services, including support groups, workshops or seminars for professionals, workshops or seminars for TBI survivors and their family members, presentations about Project services, and other types of outreach activities. Collectively, the sites responded to inquiries from almost 7,000 individuals and provided 7,400 referrals in response to those inquiries. Staff of the seven sites convened a total of 192 support group meetings during FY03-04.

The TBI Project sites provided 76 seminars and workshops to over 2,300 professionals over the course of the year. Including preparation time, logistics, travel, and presentation, staff invested about six hours per workshop or seminar. Site staff also provided 74 workshops/seminars to approximately 2,300 participants and their family members during the year.

Over the course of FY03-04, the seven sites provided a total of 136 outreach presentations to 1,752 attendees. The sites also developed and distributed over 10,000 copies of TBI Project newsletters and marketing materials during the year. Staff at the four original sites, in particular, noted that their outreach efforts had dropped considerably in the last year. Well established in their communities after 14 years of operation, the reason these sites gave for the decrease in outreach effort was the

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decrease in funding available to support Project activities. Instead, given the amount of funding available to the sites, staff chose to focus on direct services to participants rather than outreach.

Cumulatively, the sites participated in a total of 147 community network meetings throughout FY03-04, an average of 21 meetings per site. TBI Project staff also described challenges to interagency collaboration that they have encountered, such as increased resistance to scheduling consortium meetings over time as consortium member agencies experienced funding cuts. Such funding reductions have two important consequences: 1) turnover within organizations as a result of reduced funding may mean that the agency—and consortium—loses the staff person who had "the passion" for working with TBI survivors; and 2) remaining staff are overworked, and thus pulling people together for case coordination or consortium meetings is even more difficult.

Recommendations for Program Improvements

The TBI Project was designed to achieve six specific goals as specified in the authorizing legislation. The findings summarized above suggest that the Project has been successful in providing and brokering services to persons with TBI within their communities and within the constraints of their current resources. The evaluation's overarching recommendation is to expand the funding for the Project to enable it to reach many more persons with TBI throughout the state. At the same time, specific program improvements can be made to help the Project more fully achieve its six goals. Recommendations presented here are organized according to the six Project goals.

1. Achieve comprehensive, coordinated public policy to design a coordinated services delivery system for adults with traumatic brain injuries. Coordinated public policy is difficult to achieve at the local level and may require additional state-level leadership. A coordinated services delivery system requires the engagement of a wide range of service agencies and programs in mental health, health care, education, vocational rehabilitation, workforce development, independent living, law enforcement, legal services, etc. While state-level MOUs and cooperative agreements alone are not sufficient to ensure that coordination happens at a local level, state-level commitment, communication, and leadership can be valuable supports to local coordination efforts.

Recommendations: Build specific service design considerations into state-level cooperative agreements or MOUs, such as specifying that the Department of Rehabilitation serve TBI Project participants through specialist counselors. Continue to build TBI training by the TBI Project into cooperative agreements, and make sure that every site has identified experts at their organization or through a community partner that can provide training to staff of collaborating agencies. Be sure that MOUs and cooperative agreements address mechanisms for state agencies to communicate with local agencies, and hold local staff accountable for making good faith efforts to implement the agreements.

2. Ensure the existence of an array of appropriate programs and services for adults with traumatic brain injuries and their families. Ensuring a full array of services requires both an understanding of the spectrum of services that persons with TBI might need, and a full assessment of the resources available in the community to address the range of needs. Most sites have identified a combination of services that they are well suited to offer, as well as a selection of community agencies with whom they can collaborate to fill some of the most obvious service gaps. However, each site is very



idiosyncratic in its approach and the extent to which specific types of services are available in one community versus another varies widely.

Recommendations: Move toward a "systems approach" to service delivery that identifies the range of services that should be in place to meet the needs of persons with TBI, and uses a systematic community needs assessment process to identify resources and gaps. Use ongoing program evaluation to identify promising and transferable practices. Provide technical assistance, and support mentorship and sharing of information and resources among sites to maximize effective use of lessons learned.

3. Place a high priority on utilizing community resources in creating opportunities for persons with TBI to live in the community and achieve their maximum potential, and for families to maintain a brain injured adult at home when possible or in other community-based alternatives when necessary. Project sites seem to have been generally successful in utilizing community resources and serving in a case management and service coordination role for their participants.

Recommendations: Have sites that have been successful in forging relationships with different types of community organizations coach other sites in strategies for developing relationships with counterparts in their local communities.

4. Assist persons with TBI to attain productive, independent lives, which may include paid employment. Currently, sites vary in the degree to which they focus on helping participants develop and continue to improve a full range of compensatory skills, typically assuming this is something that has been addressed through prior rehabilitation services. Assisting individuals with TBI to become more productive and independent often involves ongoing work on acknowledging and coping with TBI-related limitations, especially since these may change over time or in response to different settings and circumstances as participants move toward community reintegration or employment. In addition, site staff may not be expert at identifying substance abuse or assessing vocational readiness.

Recommendations: Include independent living skills training and individualized assistance in developing and improving compensatory skills within the core services provided by the project, or require that they be addressed directly through collaboration with community partners. Identify a common prevocational/vocational assessment tool to identify work readiness skills and needs and train staff in how to administer it. Provide site staff with training on using the Michigan Alcoholism Screening Test (MAST), Drug Abuse Screening Test (DAST), or other standardized tools to identify participants who have potential substance abuse problems.

5. Participate in a statewide uniform database for the TBI program in order to measure the effectiveness of the TBI sites and a coordinated service approach, as well as monitor the progress of the statewide implementation of Chapter 1023, Statutes of 1999 (AB 1492). The project has made considerable progress in implementing uniform data collection through the use of the common assessment form, the CIQ, and a common customer satisfaction survey. Nonetheless, the database could benefit from numerous improvements (see Recommendations for Data Collection and Evaluation below for more detail). In addition to improvements in uniform data collection, another important aspect of implementing common measures is to establish a routine for using the data to monitor progress and inform program improvement on a regular basis.

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Recommendations: Use technology to generate routine reports that provide monitoring information across the project as a whole as well as for each site, and provide timely feedback on performance to the sites. Use performance information to identify areas of technical assistance needed by the sites and to inform funding decisions. Use the contracting process to require explicit program improvements by specifying required program components and having sites specify how they will address these requirements in their funding proposals. Re-compete the contracts periodically to encourage continuous program improvement.

6. Serve a population that is broadly representative with regard to race and ethnicity of the population with traumatic brain injury in the geographical service area. Under the current level of funding, outreach is not a high priority for most sites as most of their resources are devoted to participant services. In order for the Project to serve a more representative population, sites need to develop community linkages with ethnic/multicultural organizations, hire bilingual staff, and target outreach to specific language and cultural communities. In addition, they may need to target education about long-term TBI service needs to the medical providers and organizations that serve ethnic and language minorities in their communities.

Recommendations: Consider a higher funding level for sites in areas with large underserved communities. Require sites to specify in their funding proposals the community linkages, targeted outreach approaches, and other strategies they will use to ensure that both the population they serve and the workforce they hire is increasingly representative of the racial and ethnic diversity within their target service areas. Consider providing training to site staff in strategies and resources for accommodating participants with limited English proficiency.

Recommendations for Data Collection and Evaluation

In the process of analyzing information that the TBI Project sites collect and report, the evaluation team examined in depth the data collection procedures used to document operations and outcomes. The following recommendations are organized around the requirements for the evaluation included in California Welfare and Institutions Code Section 4353-4359.

1. The department, with the advice and assistance of the working group, shall develop an independent evaluation and assist sites in collecting uniform data on all participants. The sites have made a major step forward in developing common intake and assessment forms that now are being used across the TBI Project. Unfortunately, other than assisting to develop a common customer satisfaction survey, further refining the set of data collected by the sites was beyond the resources available for this evaluation effort. The existing data collection forms, along with the quarterly reporting system for site statistics, still fall short of effectively documenting the Project's services and outcomes in some areas. Limited instructions exist to ensure common definitions of the data items across sites, thus site staff have adopted inconsistent definitions in some instances that weaken the validity and usefulness of the data they do collect. Further, DMH lacks the resources to adequately analyze information generated by the existing quarterly reports in order to use it effectively for ongoing monitoring, feedback, and oversight of Project services.

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Recommendations: Assuming the Legislature continues to invest in the TBI Project to provide much needed services to TBI survivors, then it also needs to invest more funds to improve data systems to document both the services provided by the sites and the outcomes of participants who use Project services. The improvements needed are varied and include the following recommendations:

- Require all sites to maintain assessment data in a consistent electronic format that can be electronically transmitted and compiled centrally across all sites;
- Establish common definitions for all of the data items that sites collect, including documentation of why they are collected and for whom they should be collected;
- Provide training to staff at every site to ensure that they understand both the definitions and data collection methods:
- Ensure that unduplicated counts of participants are available in the quarterly reporting system for all services included in that system;
- Refine both the assessment data set and the quarterly site statistics to include reason for termination from the Project; and
- Provide the sites with training on how to use the data they are collecting for their own management and internal evaluation purposes.
- 2. The evaluation shall test the efficacy, individually and in the aggregate, of the existing and new project sites in the following areas:
 - (A) The degree of community reintegration achieved by participants, including their increased ability to independently carry out activities of daily living, increased participation in community life, and improved living arrangements.

The CIQ appears to be a useful instrument for measuring community reintegration and participation in community life, and site staff have succeeded in implementing use of this assessment tool on a regular basis. This assessment tool, however, does not directly address participants' ability to carry out activities of daily living. For the most part, individuals served by the TBI Project are independent in Activities of Daily Living (ADLs), but many have limitations in Instrumental Activities of Daily Living (IADLs). The CIQ captures some—but not all—of the IADLs. The TBI Project's current assessment data set includes a detailed question about living arrangements. In some cases, however, a change from one category of living arrangement to another can be ambiguous in terms of degree of community integration for the individual and thus can only be interpreted by those who have knowledge of an individual participant's situation. Finally, given the timing of implementing a

⁴ These are light housework, laundry, meal preparation, transportation, grocery shopping, using the telephone, medication management, and money management. Lawton, M.P. and E.M. Brody. "Assessment of Older People: Self-Maintaining and Instrumental Activities of Daily Living," <u>The Gerontologist</u>, 9: 179-186, 1969. See: http://research.aarp.org/health/ib32 disability.html



³ These are eating, bathing, dressing, toileting, and transferring. See: Joshua M. Wiener, Raymond J. Hanley, Robert Clark and Joan F. Van Nostrand. "Measuring the Activities of Daily Living: Comparisons Across National Surveys, Executive Summary," in *Journal of Gerontology: SOCIAL SCIENCES* (November 1990, Volume 45, Number 6, pp. 229-237). http://aspe.hhs.gov/daltcp/reports/meacmpes.htm

common data collection system and the length of evaluation, the observation period was too short to document these kinds of outcomes for many of the participants.

Recommendations: Change the evaluation and TBI Project data collection requirements to include IADLs and/or other measures of participant functional abilities. Consider whether changes in ability to drive or use public transportation independently should also be collected. Revise the assessment form to capture whether changes in income and living situation at follow-up were positive or negative. These changes would allow the site manager, program monitor, and or evaluator to assess the impact of TBI Project services on these particular outcomes. In addition, the evaluation should be continued in order to document participant and program outcomes over a longer observation period.

(B) The improvements in participants' prevocational and vocational abilities, educational attainment, and paid and volunteer job placements.

The current TBI Project assessment form includes a single data item to capture changes in prevocational and vocational abilities, namely a question about the participant's employability. The form does not collect information about attending college, and educational attainment is assessed using categories (e.g., Associate Degree, Bachelor's degree), which do not capture attainment of more short-term education goals or allow for documentation of courses completed, additional semesters or years of education, or other smaller increments of attainment. Finally, the form collects information on gross changes in employment (i.e., entering and leaving a job, from part-time to full-time), but no other positive employment outcomes such as increases in hours worked per week, hourly wage or overall income, nor does it include any information about participation in volunteer work. These kinds of changes take time, and given the timeframe for implementing a common data collection system and the timing of the evaluation, the observation period was too short for these improvements to have occurred for most participants.

Recommendations: Revise the assessment form to include information about wages, hours and participation in volunteer work, attending college, and other indicators of educational attainment. Identify and consistently use a standardized assessment tool for measuring changes in prevocational and vocational abilities or "employability." Continue the evaluation over a longer time period to continue to document outcomes that take a year or more to accomplish.

(C) Participant and family satisfaction with services provided.

The contractor organizations, for the most part, have routinely collected information about customer satisfaction, but these were not consistent across the TBI Project sites. The evaluation designed and implemented a customer satisfaction survey of participants. Other than in site visit interviews, however, the evaluation did not assess family or caregiver satisfaction with Project services.

Recommendations: Routinely assess participant satisfaction with services provided across all sites using the TBI Project customer satisfaction survey that now exists. Develop and implement a consistent customer satisfaction survey to be completed by family members (or other caregivers if family members are not available).

(D) Number of participants, family members, health and social service professionals, law enforcement professionals, and other persons receiving education and training designed to

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improve their understanding of the nature and consequences of traumatic brain injury, as well as any documented outcomes of that training and education.

The Project's quarterly site statistics summary includes the number of individuals who participate in site-sponsored training activities, by audience type. However, documenting the outcomes of that training and education has been beyond the resources of the sites.

Recommendation: Design a simple assessment of TBI Project education and training outcomes to be included in future evaluation efforts.

Conclusion

Using \$1.1 million in DMH funding, plus another \$228,000 in DR funding, the seven TBI Project sites served 610 participants with moderate to severe impairments from TBI in FY03-04. Evaluation results show that virtually all participants experienced at least some improvement in community reintegration after enrolling in the Project, with participants at some sites experiencing substantial changes in their ability to take care of themselves at home, socialize with friends and family, and participate in community activities. Almost three-quarters of participants in the evaluation sample saw at least one improvement in their lives, whether it was securing a more stable source of income, finding a job, or moving into a more independent living situation, while only 20% experienced at least one negative change over time. Further evidence of the impact of the Project on the lives of TBI survivors is the overwhelmingly positive ratings and comments submitted on the customer satisfaction survey.

In addition, the TBI Project sites provided information and referral services to 7,000 TBI survivors, caregivers/ family, and professionals across the state and nation. They also provided TBI education to more than 2,000 professionals and a similar number of TBI survivors and their family members in their local communities.

The recommendations presented above recognize the value of the TBI Project's contribution, while also recognizing that the program can be improved in a number of areas and that the evaluation was restricted in its ability to document outcomes by limitations in the available data and resources. The program offers great promise for addressing what are otherwise critical unmet needs of TBI survivors, helping them to maintain and increase their community reintegration, while also providing significant community education services. The evaluation suggests that the program is sufficiently successful that its expansion to reach more participants would be a good investment, but only if part of that investment is also targeted at improvements that maximize program benefits and that improve data collection and reporting efforts to document those benefits.

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